LINDA LINGLE
GOVERNOR OF HAWAII

CHIYOME L. FUKINO, M.D.
DIRECTOR OF HEALTH

STATE OF HAWAII
DEPARTMENT OF HEALTH
STD/AIDS Prevention Branch
3627 KILAUEA AVENUE, ROOM 306
HONOLULU, HAWAIII 96816-2399

In reply, please refer to:
File:

June 2005

Proposed Change to Named HIV Reporting in Hawaii

Background:

AIDS has been reportable by name in Hawaii since 1983. HIV has been reportable in Hawaii since 2001 using a code based system called the Unnamed Test Code (UTC). Since this time Hawaii's physicians, laboratories, health care facilities and staff of the HIV/AIDS Surveillance Program of the Department of Health have worked hard to make the UTC reporting system work effectively so that we have reliable, verifiable data that can be used for a variety of purposes. These include understanding as accurately as possible the HIV epidemic in Hawaii, who is infected, how, where, who's at risk etc, planning for the range of HIV prevention and care services in response to this epidemiology, obtaining appropriate service funding from state and federal government and, evaluating program successes and ongoing and changing service needs. After almost 4 years of collecting data using the UTC Hawaii still does not have validated HIV data that can be used for our own programmatic purposes or to apply for external funding.

For UTC reporting data to be considered reliable and valid it must be evaluated by criteria established by CDC. Hawaii's UTC system has never met the criteria. Although exceptional efforts have been made it seems unlikely that it will be anytime in the future. For our HIV data to be deemed valid we need to be able to de-duplicate Hawaii cases that may have also been reported more than once in this state and in other states as well. The use of the UTC precludes the possibility of such de-duplication in most cases. Duplicate case counting can not be assessed in states with code-based reporting because communication about these cases cannot be conducted between areas with codes, or between areas that use names that must communicate with code-based systems.

The Department of Health is now proposing to make changes to the Hawaii Administrative Rules **(§11-156-8.8 and §11-156-8.9)** section **§11-156 and Exhibit A, B and C** to require HIV reporting by name and change it from HIV reporting by UTC. Named HIV reporting would commence after the formal process of changing the rules.

In order to better inform the HIV and the broader community about a variety of issues related to the proposed reporting change a question and answer section is provided below.

Changing to Named HIV Reporting in Hawaii
Questions and Answers

1. What is the current AIDS and HIV case reporting system in Hawaii?

In Hawaii AIDS cases have been reported by name by physicians since 1983. Low CD4 counts (<200 cells/ul and/or 14%) have also been reported by name by laboratories since 1998. Laboratory reporting of low CD4 results improves the completeness of AIDS reporting as these laboratory values indicate an AIDS case. HIV cases have been reported by laboratories and physicians using an Unnamed Test Code (UTC) since September 2001. In the more than 20 years of AIDS reporting by name in Hawaii there has never been a security breach or inappropriate disclosure of patient information. The current Administrative Rules, 11-156 on HIV reporting can be viewed at: **http://www.hawaii.gov/health/about/rules/11-156.pdf.**

2. Are other diseases reported by name in Hawaii?

Yes, almost 60 different diseases are reportable by name in Hawaii. These include STD, hepatitis, chicken pox, TB, leptospirosis, mumps and measles for example.

3. What reporting systems are used in other states?

All states have had named AIDS reporting since the 1980's. All states have now implemented some form of HIV reporting. As of January of 2005, 38 states and 5 territories have adopted named HIV reporting, 5 states have adopted name-to-code based systems, and 7 states, Philadelphia, and the District of Columbia have adopted systems that use coded identifiers. In the 14 areas using codes, 13 different codes are used. Several of the latter, including California are changing to named reporting.

4. What change is being proposed for HIV reporting?

With the change of Administrative Rules laboratories providing HIV services and Hawaii's health care providers would commence confidential reporting of all HIV cases to the HIV/AIDS Surveillance Program by patient name. These reports would be based on confirmed HIV tests including those by Western blot and PCR/viral load.

5. How will security and confidentiality of reported HIV/AIDS cases be assured?

The HIV/AIDS Surveillance Program maintains absolute confidentiality of HIV/AIDS case information at all times. Confidentiality guidelines recommended by CDC are followed. They include policies and procedures for the security and confidentiality protection of the data, limiting access to electronic databases; password-protected computers systems; secured storage and destruction of paper copies containing identifiers; procedure for collecting, transferring, analyzing and disseminating data. In Hawaii only staff of the HIV/AIDS Surveillance Program, bound by signed confidentiality agreements, have access to any HIV/AIDS data.``High level security" measures protect the office, room and computer system where the database is kept.

No computer with HIV/AIDS reports is linked to the internet. Only aggregate statistical HIV/AIDS data is ever released, never information that could identify individuals. No breach of confidentiality has ever occurred in the Hawaii HIV/AIDS Surveillance Program since its inception in the 1980's. Federal laws including HIPAA and Hawaii laws provide strong legal protections for confidentiality of medical information and Hawaii State law has specific confidentiality provisions related to HIV/AIDS. See Section 325-101, Hawaii Revised Statutes.

6. Are names of individuals with HIV/AIDS in Hawaii sent to CDC or elsewhere?

No. Data sent to CDC does not include names. Rather it uses a non reversible, non identifying code system called Soundex. Personal identifiers are irreversibly encoded, and records are encrypted before data are sent to CDC. Thus, CDC does not possess patient names or other personal identifiers.

7. Will there still be anonymous HIV testing in Hawaii when named HIV reporting starts?

Yes, CDC recommends and Hawaii strongly concurs that anonymous testing will continue to be made available in Hawaii. Individuals testing anonymously can remain unreported by the testing program. All cases of HIV would be reported when individuals enter HIV medical or care services.

8. Could use of the UTC HIV reporting system affect future federal HIV funding for Hawaii?

Yes. Nationally, it is recognized that validated HIV data used in conjunction with AIDS data is a better indicator of the epidemic in any state. CDC has not accepted code based HIV data from Hawaii or any other state. It is probable that future federal HIV funding formula will increasingly incorporate HIV to determined funding allocations. This makes sense for the funding to follow the epidemic. The Ryan White CARE Act will likely be reauthorized this year and the Administration recently released its Principles for Reauthorizations which include reference to use of HIV reporting data for funding allocations. If Hawaii continues with a system that does not met CDC criteria for a valid system then we could loose funding. Hawaii currently receives about $ 2.1 million from CDC for the HIV prevention program and $3.4 million from Title II of the Ryan White CARE Act, the primary source of funding for Hawaii's care services and HDAP program.

9. What is the CDC policy on accepting data from states using coded HIV reporting?

CDC policy is to accept HIV data only from areas conducting confidential named HIV reporting because named reporting has been evaluated and found to be highly accurate and reliable. CDC has concluded that only named HIV reporting has been scientifically validated for use by states for inter-jurisdictional de-duplication. CDC particularly resists use of any HIV reporting system that has not met evaluation criteria

for the purpose of allocating funding. This CDC policy was re-confirmed in July 2005 by a letter from CDC Director, Dr. Julie Gerberding.

10. What are HIV/AIDS data used for that require them to be accurate?

Surveillance activities provide demographic, laboratory, clinical and behavioral risk data that are used to identify populations at greatest risk for HIV infection. There are three primary uses of surveillance data: 1) epidemic monitoring to estimate incidence and prevalence of HIV-related morbidity and mortality in the population, estimate incidence of HIV infection, and identify change and trend of HIV transmission and populations at risk; 2) prevention and care planning to target prevention interventions care services and evaluate their effectiveness and to facilitate access to health, social and prevention services; and 3) allocation of federal HIV program funds for prevention, care and treatment services, including the Ryan White CARE Act (RWCA).

11. What further needs to happen for Hawaii to obtain reliable HIV data?

- Change the Administrative Rules to mandate named HIV reporting from health care providers and laboratories
- Provide extensive training to health care providers and laboratories on named HIV reporting
- Convert current UTC HIV reports to named HIV reports, remove cases that have progressed to AIDS, de-duplicate our cases in state and with other states and
- In approximately 18 months evaluate Hawaii's system and have our data accepted by CDC

This document and the draft of proposed revisions to the HIV reporting rules can be found on the web at:

Comments and questions related to named HIV reporting can be addressed to Peter Whiticar at whiticar@lava.net

Peter Whiticar, Chief
STD/AIDS Prevention Branch
Hawaii Department of Health